

CRS Parent Connection

Alabama Department of Rehabilitation Services



Volume 13, Number 3

Summer 2005

Mandy Jennings, CRS Parent Consultant

Hello! My name is Mandy Jennings and I have been the parent consultant at the Opelika CRS (Children's Rehabilitation Service) Office for two years. The week I was offered the position at CRS was a busy week. I was offered a position with a financial institution, a law firm and a marriage proposal. I chose to follow my heart and accept the position at CRS. While this is a challenging position, it is also one of the most rewarding I have ever had. I enjoy making people smile and helping them to see they are not alone. CRS was an important member of my family long before I became a parent consultant. As for the marriage proposal, I accepted that also. Tim eagerly welcomed the three of us into his life and home. I tease Tim and the children that they just keep me around to have each other. Tim helped me to accept many things that I had not, and he is by my side each step of every day.

I have two children, both boys. The oldest, Jamie, is 13, a teenager. I know, saying he is a teenager sums it up fairly well. There are really no words to

express living with a teenager. My youngest son, Brett, is 11. When Brett was nine months old he was diagnosed with tuberous sclerosis, a rare genetic disorder. I will never forget how alone I felt when the doctor told me the news; I had so many questions, and there seemed to be no answers. As I held Brett close to me in the doctor's office I realized that God trusted me to care for this precious angel, and I would not disappoint Him. The next years would bring a new challenge each day with seizures, medications, physical therapy, occupational therapy, speech therapy, doctor visits and hospital stays—life was anything but monotonous.

Even though Brett uses a wheelchair for mobility and is not verbal, he has those looks that are worth a million words. If he likes you, there is no doubt—if he does not like you, there is still no doubt. He jabbers in his own language, and it is your fault, not his, if you do not understand what he is saying. It is hard sometimes to let Brett be a kid, but I remind myself he was a little boy before he was a child with special



needs. He loves to ride on the go-cart with Jamie and is Jamie's #1 fan at the football games—not to mention he wins the hearts of all Jamie's friends, especially the girls. Jamie is the best brother Brett could have.

We vacation, shop and enjoy life as much as any other family. We seldom let life slow us down; we load up and go. If you see a very happy little boy in a red wheelchair going through the mall, putt-putt, amusement park, etc. please feel free to stop and speak to us. If you are in the Opelika area, I encourage you to call me (334)745-7579 or (800)568-8428 or come by my office.

(Mandy continued on page 3.)

Inside....

New CRS Audiology Specialist	P. 3
State PAC Meets	P. 4
Family Voices	P. 5
Let's YAC About It	



2005 YAC Graduates	. P.	7
Parent Connection of Alabama	. P.	8
Parent Connection Enrollment Form	. P.	9
Keen Your Youngsters on the Go	Р	11



Editor: Susan Colburn

State Parent Consultant

Layout & Design: Joann Brothers

Resource Assistant

Contributing Writers: Mandy Jennings

> Alice Sette Jennifer Thomas Kayla Beard Stacy Brock Ashley Farr Vonda Reeves

Address Inquiries To:

Susan Colburn

Fax:

Children's Rehabilitation Service 2129 East South Boulevard Montgomery, AL 36116 Phone: (800)846-3697

(334)613-2284 (334)613-3553

E-Mail: scolburn@rehab.state.al.us

Parent Connection is a complimentary newsletter published by Children's Rehabilitation Service for families of children with special health care needs. The goal of this newsletter is to increase communication and share information about children with special health care needs and their families. The newsletter reflects a family-centered theme throughout and serves as a forum for family members to share information, thoughts, feelings, concerns, etc. Nothing printed or implied in this publication constitutes an endorsement by the Alabama Department of Rehabilitation Services.

This material is available in alternate formats upon request. Alternate formats include braille, large print or audio tape and may be obtained by calling the phone numbers listed above.

In the provision of services and employment practices, the Alabama Department of Rehabilitation Services does not discriminate on the basis of sex, creed, national origin, religion, race, age or disability.

Children's Rehabilitation Service Office Locations



Andalusia CRS

Linda Foster, parent consultant 1082 Village Sq. Dr., Suite 2 Andalusia, AL 36420 1-800-723-8064

Anniston CRS

1010 Christine Ave., Suite 250 Anniston, AL 36207 1-800-289-9533

Birmingham CRS

Tammy Moore, parent consultant 236 Goodwin Crest Dr. Birmingham, AL 35209 1-888-430-7423

Dothan CRS

Vonda Reeves, parent consultant 795 Ross Clark Circle, NE Dothan, AL 36303 1-800-677-9123

Gadsden CRS

Sandra Hazzard, parent consultant Odessa Taylor, parent consultant 1100 George Wallace Drive Gadsden, AL 35903 1-800-289-1353

Huntsville CRS

Rita Cobb, parent consultant 407 Governors Drive, SW, Suite B 7 Bemiston Ave. Huntsville, AL 35801 1-800-283-9352

Jackson CRS

Sharon Beech, parent consultant 1506 College Ave. Jackson, AL 36545 1-800-283-8140

Mobile CRS

Penny Strickland, parent consultant 1610 Center St., Suite A Mobile, AL 36604 1-800-879-8163

Montgomery CRS

Sandra Hazzard, parent consultant Monica Jackson, parent consultant 2127 E. South Blvd Montgomery, AL 36116 1-800-568-9034

Muscle Shoals CRS

Sharon Curry, parent consultant 1450 E. Avalon Ave. Muscle Shoals, AL 35661 1-800-285-9924

Opelika CRS

Mandy Jennings, parent consultant 516 W. Thomason Circle Opelika, AL 36801 1-800-568-8428

Selma CRS

2906 Citizens Parkway Selma, AL 36701 1-800-967-6876

Talladega CRS

Sandra Hazzard, parent consultant

Talladega, AL 35160 1-800-947-7140

Tuscaloosa CRS

Vivian, Spears, parent consultant

1110 Sixth Ave., East Tuscaloosa, AL 35401 1-800-723-0490

(From the Director's Chair will return with the next newsletter.)

New CRS Program Specialist for Audiology

Hi. My name is Alice Sette and I'm the new CRS program specialist for audiology. I graduated in 1982 from Dalhousie University, in Halifax, Nova Scotia. My husband Joe, who's in the military, and I moved to Fort Rucker, Alabama in 2001. Moving here enabled me to start work on my doctoral degree in audiology through the University of Florida. I became a full fledged Florida Gator in 2004.

I joined CRS in the Dothan office in 2003 where I worked to re-establish the hearing and hearing aid programs for the Dothan/Andalusia districts. Prior to coming to Alabama we lived in Kuwait for four years. In Kuwait, I worked for a Canadian university that was contracted by the Ministry of Health in Kuwait to set up a model of rehabilitation care for the country. In the past I have also been employed as an instructor adjunct to the faculty of medicine at Queen's University and did a significant amount of teaching and

lecturing to audiologists, medical students and other health care professionals. I was also responsible for setting up a Northern Outreach Program to provide audiology services to Cree residents in some of the James Bay and Hudson Bay communities of northern Ontario. I've been privileged to work with many hearing impaired children and their families over the years. Some of these children have been a gift to me personally in the way they've touched my life, and many have made a lasting impression.

Joe and I love the Alabama hospitality we've received here and the year-round sunshine. And I'm especially enjoying my work with CRS. I want to take this opportunity to thank the CRS staff of the Dothan/Andalusia offices for their continuing patience and support. And I want to acknowledge the talented CRS audiologists situated around the state. Alabama is very fortunate to have them. Finally, I want to thank our CRS



children who've made me feel welcome and given me a place to call home.

Please call me if I can help you at any time. I am continuing to work out of the Dothan office.

Alice Sette, MPA, Au.D. CRS Program Specialist for Audiology 1-800-677-9123

(Mandy continued from page 1.)

You can also reach me via email at mjenning@rehab.state.al.us. Also, you are welcome to come to our local Parent Advisory Committee (PAC) meetings for information, friends and treat food. Please let me know if there is anything I can do to help.

Mandy Jennings CRS Parent Consultant



Traveling Together on Highway 2010

Creating Healthy Tomorrows for Children and Youth with Special Health Care Needs

> July 14-15, 2005 Sheraton Birmingham Hotel

If you are interested in coming to the conference please contact Susan Colburn at 1-800-846-3697. Parent/youth scholarships are available on a first-come, first-served basis. We look forward to seeing you there.

State PAC Meeting

The State Parent Advisory Committee (SPAC) met on Saturday, June 11, 2005. Susan Coburn, CRS state parent consultant, welcomed the parents, parent consultants and Children's Rehabilitation Service staff attending the meeting. Dr. Cary Boswell, CRS director, addressed funding issues and their impact on CRS. Other CRS staff reported on the new CRS record keeping software, hearing aid dispensing policy, Maternal Child and Health Block Grant/Needs Assessment and the upcoming 2010 conference. Local reports were given by SPAC representatives and parent consultants telling of activities in the local PACs. The guest speaker was Ann Cosby, parent of a child with special health care needs. Ann shared making family memory books and then led the group in designing a page for their own memory books.

If you are interested in becoming involved in the PAC, contact the parent consultant in you local CRS office.



Dr. Cary Boswell brings the committee up to date on CRS news.



Julie Preskitt reports on the information gained in the 5-year needs assessment.



PAC members listen as local representatives give reports.



Ann Cosby assists some of the committee in making their memory page.



Emergencies and Disasters Keeping Children and Youth with Special Health Care Needs Safe

Though we hope emergencies and disasters never happen, recent weather emergencies in Alabama have reminded us that they can and do. All families should have emergency plans for their children. If you are a parent of a child with special health care needs, your emergency plan will probably be more complicated. This will be the case if your child or youth:

- Depends on electricity to breathe, be fed, stay comfortable
- Cannot be moved easily because of a medical condition or attachment to equipment
- Uses a wheelchair, walker or other device to move
- Cannot survive extreme temperatures, whether hot or cold
- Becomes afraid or agitated when sudden changes happen
- Cannot get out of an emergency situation alone for physical or emotional reasons.

Everyone in your home should know what to do in an emergency, whether it's a power outage, fire or natural disaster, such as a flood or tornado.

- Instructions: Prepare simple, one-page emergency instructions and update as things change. Include information about exits, fire extinguishers and power shutoffs. Place instructions where they can be seen and have everyone practice.
- Medical Things: Make sure your child's medicine, medical records and important equipment are easy to grab if you have to leave suddenly.
- Electricity and Telephone: Tell your local utilities that your child depends on electricity. Ask them to "flag" your household and to bring power back quickly to your home. Get a generator if you can.
- Emergency Services: Visit your nearest emergency center (fire

- department, rescue squad, 911 facility). Tell them about your child. Invite them to your home to become familiar with the situation and to give you emergency tips.
- Local Hospital: For some children or youth, the nearest hospital might be the safest place to be in a disaster, so you and your doctor should work out admitting procedures to avoid an ER wait.
- Emergency Box: Keep a box containing flashlight, water, blankets, with necessities and comforts for your child, close to an exit.

For more information about emergency planning both in the home and when away from home, visit the Family Voices website at www.familyvoices.org.

For information about Family Voices, please contact the Alabama state coordinators Susan Colburn (334-613-2884, scolburn @rehab.state.al.us) or Jerry Oveson (251-438-1609, oveson@bellsouth.net).

Please add me to your new	sletter mailing list.
Name:	
Agency:	
Address:	305
City/State/Zip:	



From the Pen of the Youth Consultant

Hello again! I hope you have been enjoying your summer; I know that I have. Well, I won't bore you with my summer plans, but I will let you know about a few things that are going on. I went to Chicago for a KASA (Kids As Self-Advocates) board meeting on June 8-11, 2005. I have really been enjoying working with KASA. Please make sure you check out the new changes that are being made to the KASA website at www.fvkasa.org

I would also like to let you all know that I have been selected to serve on the Governor's Commission on Disability. People with disabilities, family members and advocates from all across the state serve on this commission, seeking to foster legislation and public policy that will have a positive influence on people with disabilities, their families and their communities. I am truly honored to have been appointed to join this commission.

Well, that's all I have for now. Continue to enjoy your summer, and I will "yac" with you soon!

> Jennifer Thomas CRS State Youth Consultant

For more information about the Let's YAC About It section of this newsletter, please contact Jennifer Thomas, CRS state youth consultant, at jthomas@rehab.state.al.us or Linda Graham, state youth coordinator, at lgraham@rehab.state.al.us. You may also reach either of them at 1-800-441-7607.

The Youth Advisory Committee

The Youth Advisory Committee (YAC) is proud to honor its graduating members for 2005. They are: Kayla Beard, Ryan Colburn, Ashley Farr, Jennifer Oveson and Jamal Jones. These graduates will be honored on Thursday, July 14, 2005 during an extraordinary YAC celebration.

What's Happenin'?

Sadness. Pride. Fear. Courage. Worry. Caring. All these thoughts are running through my heart and my mind. Why? My cousin, Jonathan Lambert, 18, left today to voluntarily serve our country. He is a member of the United States Army doing his basic training at Fort Sill, Oklahoma. He will most likely be going into bomb disposal. I am sad that he is going—he is sad to be leaving his family, but realizes the need to "grow up." I am proud because of what he and numerous other men and women have chosen to do-protect my freedom and yours. He is proud to have earned an Army scholarship and be able to serve his country. I am fearful because bomb disposal? I know the "real" Jonathan (ha! ha!), and I hear stories of bombs going off everyday in foreign lands he has, too. He is also fearful because of being away from home and flying on an airplane. Making your own decisions can be scary for any of us. I love his courage. He gives me strength when he thinks I am giving it to him. His courage to do what he feels is right amazes me. Lastly, I will worry about him until he comes home safely. He will continue to worry about me and my life's direction, and about both of us becoming well rounded adults. I love and admire him.

> Kayla Beard YAC Member

On April 26, 2005 I was lucky enough to be able to meet Deidre Downs, this year's winner of the Miss America Scholarship Program. Miss Downs came to Northeast Alabama Community College where I am a student and spoke.

She talked about her life and gave a little insight on what it's like to be M is s America. M is s Downs is very down-to-



earth and friendly. She posed for several photos with me and even let me wear the official Miss America Crown, which was a dream come true for me. I will never forget the whole incredible experience.

Stacy Brock YAC Member

(YAC news continued on page 8.)

YAC ...

YAC... YAC...



Honoring the YAC Graduates!



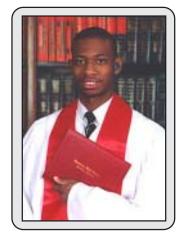
Jennifer A. Oveson Baker High School Mobile, AL



Kayla S. Beard Sparkman High School Madison, AL



Ryan S. Colburn Jefferson Davis High School Montgomery, AL



Jamal D. Jones Theodore High School Theodore, AL



Ashley R. Farr **Brookwood High School** McCalla, AL



Parent Connection of Alabama

Parent to Parent programs provide emotional and informational support to parents of children with special health

care needs. Veteran parents are carefully matched in one to one relationships with parents who are newly referred to the program. The Parent Connection network is a

growing resource for families who have a child(ren) with special health care needs. The strength of Parent to Parent comes directly from the parents who dedicate themselves to its continuing success.

A match is a one-to-one match relationship between a support parent of a family member with special needs and a parent who is looking for support and information from another parent with similar family and disability experiences. Because the quality of the matched experience depends on a number of different factors, Parent to Parent programs make parent matches with great care. Parents who are interested in being matched with a supporting parent can complete the form in this newsletter or talk to the parent consultant at their local CRS (Children's Rehabilitation Service) office. Referrals and matches are never made without the permission of the parent seeking the support, and

"I was not the only one

things I do."

going through some of the

anonymous referrals are not accepted. In order for the coordinator to ensure the most successful match, information will be

gathered from the referring parent about the child, his or her special needs, the parent's needs and/or situation, and specific challenges.

Sharing family experiences with others in similar circumstances is an important source of social support. Following is a communication received from Teresa Brady, a grandmother of a child with special health care needs.

"Ever since the birth of our special needs granddaughter, I have tried to connect with someone to whom I could talk who had a child with a similar syndrome or even a grandparent that was going through some of the same things I was. I thought it would help me deal with the "daily grind" of raising a special needs child just to talk to someone. A few months ago, I finally was contacted and was told that a

connection had been made. I called the lady, who is a grandmother of two special needs grandchildren. We talked a long time. It did, indeed, give me moral support to know that I was not the only one going through some of the things I do. She was very glad to get to know me, too. As you well know, raising a special needs child can be not only physically but also emotionally exhausting. For me, it helps to "vent" some things that only someone who has been through it can identify with. I encourage you to make an effort, if you haven't already, to make parentto-parent connection work for you."

The Parent Connection network provides a continuum of support—providing parents with one-to-one emotional and informational support from another parent who has been there. To become a part of our network, simply complete the form found on pages 9 and 10 of this newsletter. When completed, return the form by mail to the address at the top of the form or give it to the parent consultant at you local CRS office.

Vonda Reeves CRS Parent Consultant Dothan, AL

(YAC news continued from page 6.)

I recently had the opportunity of a lifetime. I was one of five Alabama students awarded the Alabama Public Television Young Heroes Award and the Marissa Feigelson Community Service Award. I received a scholarship, a laptop computer and many other gifts. I was on TV and spent two days with Miss America. We went to the Birmingham Civil Rights Museum, Birmingham Zoo, Vulcan Park and Books-A-Million where we received a \$100 gift card. At Vulcan Park, we were

treated to breakfast sponsored by Honda and presented the Key to the City. We participated in a press conference and then had lunch with over 500 Birmingham Rotary Club members. They really treated us like stars. It was a complete honor and I had a blast!



Ashley Farr YAC Member

Youth Power Workshop

Hey, you! Are you interested in learning how to speak up for yourself and get your point across? The Youth Power Workshop is designed just for you. It will take place from 1:00-3:00 p.m., July 29, at the CRS office in Tuscaloosa. Please contact Linda Graham for more information.



Parent Connection A Parent to Parent Network of Alabama CHILDREN'S REHABILITATION SERVICE

2129 East South Blvd., Montgomery, Alabama 36111 TEL: 1-800-846-3697



Connecting families of children with special health care needs across Alabama to provide support, information, and training.

Please match me with an ex	•	•	provide support to others? s No	
PLEASE ONLY SHARE II	NFORMATION THAT YOU F	EEL IS RELEVANT IN	BEING MATCHED WITH OTHER PA	RENTS
FAMIY INFORMATION: First	Name	Last Name		
Mailing Address				
Street Address				
City	State	ZIP	County	
Home Phone	WorkPhone	Email	FAX	
RaceAfrican American	CaucasianHispanio	cNative American	AsianOther DOB	
Last Grade Completed	Degrees or Certifica	tion	_Occupation	
Marital StatusMarried _	SingleWidowe	dDivorced	_SeparatedRemarried	
Relation to ChildMothe	rFatherBirthI	FosterAdopted	_SiblingGrandparentOther	
Personal Experience/InterestPromoting Legislation GroupSupported Employ	_Public PolicymakingS	peakingStart	sionIndependent Living ing or Maintaining Parent Support	
Organizations(Check all that aPriends For LifePOther			Disability Specfic Organization Support GroupTAP	
CHILD(REN) WITH SPECIAL	NEEDS: First Name(s)		Last Name	

_____Male___Female___ **Disability was diagnosed**___Before Birth___At Birth___At the age of_____

Primary Disability or Condition:____ADD/ADHA____Autism___Cerebral Palsy____Cleft Lip/Palate

_Down Syndrome_____Fragile X_____Genetic Disorder_____Hearing Impaired/Deaf __Multiple Disabilities_____Neurologic Disorder_____Seizure Disorder_____Spina Bifida

REV 10/16/01

___Visual Impairment/Blind____Other___

DOB___

(Parent Connection continued from page 9.)			
Please circle all items that best describ <u>Assistive Technology</u> Augmentative Communication	e your child: Hearing Cochlear Implant	Type of School Program Early Intervention	
	•	Home Schooling	
Computer	Hearing Aid		
	No Hearing/Deaf	Not Attending School	
-	Partial Hearing Loss	Public School	
Behavior	Typical Hearing	Private School	
Aggressive		Resource Room	
Overactive		Regular Classes	
Typical for Age		Self-Contained Class	
Underactive	Medications(list)	Special Education –Preschool	
		Speciallized Child Care	
Diet		•	
			
Feeding Skills	Mobility	Special Medical Equipment	
Fed by Others	Crawls/Scoots	Apnea Moniter	
Feeding Problems	Delayed Mobility	Heart Monitor	
Feeding Tube	Wheelcahir-Needs Assistance	I.V.	
Gastrostomy Tube	Wheelchair-Self Operated		
		Oxygen Suction	
No Help Needed	Typical Mobility for Age		
Regular Diet	Walks with Supportive Device	Ventilator	
Some Help Needed	Walks Independently	Other	
Toilet Skills	Special Procedure	Treatments	
Catheterization	Colostomy	Auditory Training	
Help Needed with Toileting	ECMO	Chemotherapy	
		Lovass Therapy	
Typical Toileting for Age	Gastrostomy		
Not Toilet Trained	Shunt	Occupational Therapy	
	Tracheotomy	Patterning	
<u>Speech</u>		Physical Therapy	
Clear and Understandable	<u>Vision</u>	Radiation Therapy	
Delayed Speech	Contact Lenses	Speech Therapy	
Difficult to Understand	Corrective Lenses	Vision Therapy	
No Communication	No Vision /Blind	Other	
Non-verbal Communication	Typical Vision		
Sign Language	Partial Sight Loss		
11.4	P. 1994		
List any surgeries related to your child's of	disability:		
Where do you go for medical care?			
Do you have insurance?YesNo	What Type?		
SSI?YesNo Medicaid?Ye	es No CRS? Yes	No VR? Yes No	
Does this child live at home?Yes	NoIf not,where?		
Other Children?YesNo Names			
Extra notes:			
I give my permission for my na	me and telephone number to be	released to another parent.	
Signature		Date	
5			

Parents and Kids



Keep Your Youngsters On The Go

Here's news that many parents may find moving:

Clearly, movement is very important for helping children grow healthy and strong. However, as children explore and interact with the world through movement, they are also developing thinking and communications skills, as well as self-confidence.

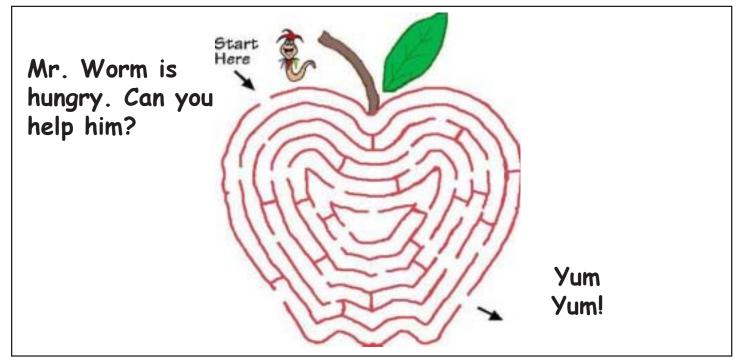
Children feel competent both physically and emotionally when they use their bodies to communicate and solve problems. Children learn problem-solving skills as they try different actions—climbing up, over, in or through. Movement is also one of the earliest ways children express their thoughts and feelings.

Perhaps most important, through movement children can develop a closer bond with their parents. There are many fun ways you can encourage your youngsters to get moving.

- Follow their movements. Babies and toddlers love when you imitate them. It makes them feel important.
- Put your baby on his belly to help him develop coordination between upper and lower body and support muscle and motor development.
- Put on different types of music and move to the beat with your young child in your arms.
 Encourage your toddler to move to music. Children this age often do not change their movements to match the music; they respond to their own internal rhythm.
- Describe your child's actions as he/she dances to the music. "Look how you bounce to the beat." This not only helps her learn new words, but also instills a sense of pride that her actions are noticed.
- Create an "obstacle course" that encourages your toddler to use a variety of skills. Have

- boxes set up for him to crawl through, pillows to climb on and blocks to run around. Doing the course over and over helps your child learn to organize his actions to reach a goal.
- Songs like *The Itsy Bitsy* Spider can help develop the use of fingers and hands.
- In the sandbox, offer your child different size pails and shovels to help her practice using her fingers and hands.
- Play with balls of all sizes.
 Figure out together which ones are best to kick, throw, play catch with and roll on.
- Act out stories using movement and dance. Good themes include animal stories, marching bands and fantasy images such as fairies and superheroes.

These suggestions come from the experts at ZERO TO THREE. You can learn more online at www.zeroto three.org.





Children's Rehabilitation Service Alabama Department of Rehabilitation Services 2129 East South Blvd. Montgomery, AL 36116 PRESORTED STANDARD U.S. POSTAGE PAID

> Montgomery, AL Permit No. 109



July 14-15, 2005 Traveling Together on Highway 2010 - Creating Healthy Tomorrows for Children and Youth with Special Health Care Needs; Sheraton Birmingham Hotel; Birmingham, AL;

Parent/youth scholarships available; Contact: Susan Colburn; 1-800-846-3697

July 24-27, 2005 2005 Annual National Conference of the Association for Persons in Supported Employ-

ment; Riverview Plaza Hotel and Mobile Convention Center; Mobile, AL — For more

information go to www.apse.org.

July 29, 2005 Children's Rehabilitation Service Youth Power Workshop; Tuscaloosa, AL;

1:00 - 3:00 p.m.; Contact Linda Graham or Jennifer Thomas, (334) 281-8780

November 14-16, 2005 Alabama Early Intervention and Preschool Conference; Sheraton Birmingham Hotel;

Birmingham, AL; Contact: Jeri Jackson, JBH50@aol.com